

295

Waiting

State's Severely Disabled and Their Families Need Help Now

By Janet Pearson
Editorial Writer

Ordinarily, newspapers don't pay much attention to anonymous mail. Occasionally, there is reason to make an exception. Last week's mail brought such a letter. Its author claims to be the parent of a severely handicapped child, and the story is convincing.

The writer was troubled about the case of the mentally retarded teen-ager who died from heat stroke after her mother took her along on errands. Reports indicated the teen, who had been left in a car for hours, also ingested various cloth and plastic items. The mother has been charged with second-degree manslaughter.

"While the Glenpool mother probably used poor judgment, we should understand the position she was probably in and what could have driven her to that position," the writer said.

"The closing of Hissom (Memorial Center) has been good for the people who perhaps should never have been in an institution and can be integrated successfully into society; however, the result has been that handicapped people who were never placed there are getting no services at all," the writer continued.



Janet Pearson

This person knows what he or she is talking about. There are thousands of Oklahoma families who are trying to take care of handicapped children on their own because it's what they want to do and what they feel they should do. But it's virtually impossible to do without at least a little bit of help, and only a handful are able to get that help. As federal and state purse strings tighten, help probably will be even harder to get.

Our middle-class parent explains: "The only thing we qualify for is the 'waiting list.' Our daughter has been on the list almost five years, and every day I hope and pray that there won't be a life-threatening accident. Our daughter must be watched every minute of the day and night. She, too, eats everything she gets her hands on and it happens very quickly. In addition, she tries to injure herself at times and has no concept of her own safety. Just leaving the room to answer the phone is taking a chance.

"We have had to resort to putting her in a 'cage' at night and sometimes during the daytime. While we have tried to make it comfortable, and she doesn't seem to mind it, I'm sure there are people who, if they saw this, would report us for abusing and neglecting this child." That is why the writer did not sign the letter.

"There is no respite program, no child care available. You can't just call a teen-age neighbor to babysit. If you do find someone willing to care for your child, it's too expensive to be affordable for more than an occasional outing. We sometimes have to take our daughter along to run errands, too. I'm also guilty of leaving her in the car while I make a quick stop."



In Oklahoma, parents like these can sign up for one or both of two programs designed to help out. But chances are they will end up like these parents — waiting.

The home- and community-based waiver program is set up to provide therapeutic, vocational, physical, daily living and other kinds of services for families with a handicapped member. Until this year, the number who could be served through this program was limited based on a complicated federal formula derived from the number of intermediate care beds in a state. That requirement was dropped this year, but now a state must demonstrate it can serve all the people included in a waiver application to receive approval. That requirement, of course, also will limit the number that can be served.

In fiscal 1994, 1,785 Oklahomans with developmental disabilities received assistance under the waiver program. Now here's the rub: Because the closing of Hissom Memorial Center was ordered by a federal court, those clients, in effect, got to move to the front of the line. The center's more than 400 former residents, who now are living in community settings, are guaranteed services — in some cases, quite costly services — while parents like our letter-writer do without.

According to the Department of Human Service's developmental disabilities division, there are 1,268 people currently on the waiver program waiting list. The division's director of administrative services, David Goodell, estimates it would cost nearly \$27 million to meet the needs of all those people waiting; the state's share of that would be 30 percent, or about \$8 million. Given that this division experienced a funding cut last year, it is unlikely an extra \$8 million will be forthcoming in future budgets.

Another program, the state family support assistance program, also offers help to families trying to care for a handicapped child at home. Cash assistance payments ranging from \$250 to \$400 a

month are made to qualifying families to be used for purposes such as habilitation (daily living) training, equipment purchases and respite care. Last year, 487 families were lucky enough to get help through this program. Currently, about 450 are on the waiting list.

Goodell said these two waiting lists (some families are on both lists) probably greatly understate the true need for such services in Oklahoma. "To get on the waiting list, families must go through a time-consuming and complicated application process, and we are somewhat candid with people that the history of these programs suggests they'll be on a waiting list for a long time," he said. Many families give up without trying. Many other families never seek out the help, deciding instead to stoically accept their situation.

The generally accepted incidence rate of serious disabilities is between 1 and 2 percent. Using that figure, there are at least 35,000 people statewide with disabilities, including as many as 10,000 in the Tulsa area.

"There are a few people who are so severely handicapped that they will always be dependent on others to take care of all of their needs and keep them safe. The state of Oklahoma must acknowledge that these people and their families need help now, and if the state denies that help, then it must take a part of the blame when a crisis occurs," the letter-writer concludes. That's a harsh, but understandable and accurate assessment.

Regardless of one's feelings about the closing of Hissom, it does not seem fair that those clients are guaranteed high-quality services on a timely basis while many hundreds of families do without services altogether. Maybe they should all get together and file a lawsuit, too.

If a society can be judged by how well it cares for its weakest members, as various political observers have suggested, then the only conclusion that can be drawn here is that we aren't doing so good.

(405) 524-4421
Oklahoma Press
Clipping Bureau
3601 N. Lincoln Blvd.
OKC, OK 73105-5411
TULSA SUNDAY
WORLD

Tulsa, OK
Sunday 241,935

OCT 22 1995